# Department of Veterans Affairs Veterans' Family, Caregiver, and Survivor Advisory Committee September 10, 2020

## Committee Members Present:

Sen. Elizabeth Dole (Chair)

Sherman Gillums Jr. (Vice-Chair)

Lourdes E. "Alfie" Alvarado-Ramos

Bonnie Carroll

Melissa Comeau

S. Joe Crittenden

Jennifer Dorn

Mona Gunn

Everett "Denton" Knapp

Dr. Robert L. Koffman, M.O.

Gabriella Kubinyi

LTG Michael S. Linnington

Hollyanne Milley

Lee Woodruff

## Committee Members Absent:

Paula Cobb

Harriet Dominique

Dr. Rebecca Porter

Katherine "Kate" Shattuck

Sarah Verardo

## **Ex-Officio Member Present:**

Mary Lazare

# Department of Veterans Affairs Staff Present:

Dr. Betty Moseley Brown Designated Federal Officer (DFO)

Toni Bush Neal, Alternate DFO

Dr. Lynda Davis, Chief Veterans Experience Officer (VEO)

Carmen Gamble

Jill DeBord

Dr. Elyse Kaplan

Dr. Luci Levkum

Christine Merna

Christopher Olson

Jim Wartski

## Elizabeth Dole Foundation Staff:

Steve Schwab

Molly Ramsey

Pavel Sullivan Neil Sumilas

Public Present: (Note- This meeting was virtual, so only callers who identified themselves are listed)

**Bob Carey** 

Alexandria Evers

Holly Ferrell

Kenneth Harman

Brandon Hofacker

Mervyn Jones

Lauren Price

Colleen Schillmaier (ERPi support)

Tori Seals

Samantha Solley

Lauren Tokarewich

Jennifer Tullis

Maggie Walsh (ERPi support)

Christa Zimmerman (ERPi support)

## September 10, 2020

Call to Order, Welcome,
Opening Remarks
Senator Elizabeth Dole

## Senator Elizabeth Dole, Committee Chair

- Senator Dole called the meeting to order at 12:59pm EDT. She welcomed members of the public and acknowledged that the committee members look forward to reviewing the comments they have submitted.
- Senator Dole asked that members, as they do their committee work, keep in mind those—especially the thousands of vulnerable military and Veteran families—who have been negatively impacted by Coronavirus.
- She thanked Secretary Wilkie and his entire team at VA for their critical role in keeping Veterans and their families safe and healthy, and importantly, in activating the fourth mission of VA to serve as backup to civilian health care providers in areas hit hard by Coronavirus.
- Senator Dole summarized the history of the committee to date. At the final meeting in 2018, the committee called for an independent national survey of the needs of military families, caregivers and survivors to fuel its next phase of work. The survey was sponsored by the Elizabeth Dole Foundation and Wounded Warrior Project. A full briefing of the results of the survey was provided at the March committee meeting. Since then, the committee has been engaged in reviewing the data, digesting the findings and translating them into draft recommendations.
- Senator Dole thanked Jenna Dorn and Melissa Comeau for serving ably as the chairs of the two subcommittees.

- As Jenna and Melissa present the draft recommendations, Senator Dole encouraged members to comment and ask questions as the recommendations are finalized for Secretary Wilkie's review and implementation.
- Senator Dole thanked Dr. Lynda Davis for working with Secretary Wilkie to fast track the process and enable the committee to present recommendations to the Secretary so quickly this month. She praised Secretary Wilkie for committing to review recommendations immediately and move them forward before the end of the year.
- Senator Dole also praised committee members for rising to the occasion and expeditiously developing the next round of recommendations to present to the Secretary on behalf of military families, caregivers and survivors.
- Lastly, Senator Dole thanked her team at the Elizabeth Dole Foundation for their assistance in providing documents and materials needed to formulate and finalize the recommendations.
- Looking ahead, as the committee moves into the new year, Senator Dole said that members will have the opportunity to work with friends at the VA and partners across the country to assess even more comprehensive gaps in services and support. The committee will take the time to invite briefings from the VA and other departments, and to meet with stakeholders to determine their challenges and needs. In other words, the committee will take a little more time to canvass the full scope of services and support in formulating the next round of recommendations.
- She said the committee should feel pleased with the progress made in such a short amount of time – in the midst of a pandemic without the ability to sit down together as a team.
- Senator Dole then called on Designated Federal Officer (DFO), Dr. Betty Moseley Brown, to address the committee.

## Federal Advisory Committee Update Dr. Betty Moseley Brown (DFO)

# Dr. Betty Moseley Brown, Designated Federal Officer (DFO)

- Dr. Moseley Brown introduced herself as the Designated Federal Officer and welcomed attendees to the virtual Federal Advisory Committee meeting. She stated that the meeting is being recorded and supported by ERPi contracted staff. She also reminded the committee that they must be recognized by the Chair for an opportunity to speak. Due to the virtual nature of the meeting, she asked that members raise their hand to have their microphone unmuted.
- Dr. Moseley Brown reminded all attendees that the discussion and voting is only for committee members.
- She told attendees that if there were any difficulties or if they wish to submit public comments, or request any forms or presentations, to please email veofaca@va.gov. Two public comments were received and would be available to all committee members immediately after the meeting.

## VA Veterans Experience Office Update

Dr. Lynda Davis, Chief Veterans Experience Office  Senator Dole thanked Dr. Moseley Brown and her team for keeping meetings running smoothly, recognizing that there is a great deal of work done behind the scenes. She then introduced Dr. Lynda Davis to give an update from the Veterans Experience Office.

# Dr. Lynda Davis, Chief, Veterans Experience Office (VEO)

- Dr. Davis thanked Senator Dole and the committee members for their dedicated and informed contributions as they offer recommendations.
- Dr. Davis gave a brief background on the committee. She mentioned that this is the second group of committee members and that this Advisory Committee began under the leadership of Senator Dole and is the first of its kind.
- Dr. Davis remarked that the committee has made some substantial and important recommendations already, and that the extensive review process required for the recommendations would be expedited as much as possible. The recommendations will then be reviewed by the Office of General Counsel and any relevant program offices before being received by the Secretary.
- Dr. Davis mentioned that customer service is her responsibility; to ensure that Veterans' families, caregivers and survivors have the best experience for care, benefits, memorial or other services. The observations, input and recommendations of the committee help meet that goal.
- Dr. Davis spoke about the focus on the employee experiences as the Veterans' families, caregivers and survivors cannot have a successful experience without employees who are well-trained and fully engaged.
- Dr. Davis talked about some of the virtual services the department now
  offers. Telehealth use has grown, and the VA must ensure that telehealth
  services are available to all Veterans and families. This includes same-day
  services for mental health, which is especially necessary to address the
  challenges of increased stress and isolation experienced by Veterans and
  caregivers due to the pandemic and also for the chronically disabled, those
  with limited mobility, and those living in rural areas with limited resources.
- The Program of Comprehensive Assistance for Families and Caregivers is a critical program touched by many of our constituents and will be briefed on during the meeting.
- Dr. Davis discussed the Vet Resources newsletter, explaining that it is distributed every Wednesday to more than 11 million Veterans and highlights what we are doing and what many of your organizations are doing. The newsletter ensures Veterans, families, caregivers and survivors are aware of services available to them, where and when they are needed.
  - For the first time, a Virtual Veterans Experience Action Center—a one stop center—was tested in Florida, giving Veterans in their homes access to VA, state and local services. This is critically

- important for rural Veterans or for when mobility issues prevent them from accessing those services.
- VA is committed to be able to serve Veterans in the communities where they live, instead of having to travel to the hospital.
- This Center:
  - Has been done in-person and now virtually,
  - Allows Veterans to sign up to receive a sequence of appointments over the phone to discuss their health and care needs,
  - Will be expanding to more states through the rest of the year (including Pennsylvania, Colorado and Arizona)
  - Will connect with Community Veteran Engagement Boards (CVEBs) and Veteran Service Organizations (VSOs) in the community.
- VA is working with the Department of Defense (DoD) to streamline and integrate medical records of service members and Veterans by compiling all the data into one profile through electronic health record modernization.
- VA is expanding analysis of the Veteran experience through VSignals surveys:
  - More than 42 surveys sent to Veterans that ask qualitative questions about their experience receiving care,
  - Provides immediate feedback and can be searched by location and topic, which allows staff to be proactive about service recovery and program improvement,
  - Dr. Davis' office will provide a summary of service recovery activities tied to the information that is received from these surveys to the committee.
- VA is attuned to the mental health and stress challenges constituents are currently experiencing, and addressing this with initiatives such as:
  - Suicide prevention month,
  - Warm handoffs for anyone who completes a survey or calls the hotline making a comment they are in trouble or at-risk,
  - o Access to the Crisis line and VA Hotlines, and
  - A Master Knowledge Management Library of Q&As that allows VA employees to provide the correct answer to inquiries quickly.
- Enhanced Quick Start Guides are being developed for caregivers and survivors, including new guide for Community Care (generically called "Choice"), which enables Veterans, families and caregivers to choose care providers outside of VA and is ideal for when there are challenges of distance or a specialist is needed.
- Dr. Davis remarked on the impressive professional caliber of the committee members and their personal lived experiences which informs everything they bring to this committee.

- Dr. Davis was appreciative of the Chair and Vice Chair for their leadership, and to Jenna Dorn and Melissa Comeau for leadership of the subcommittees.
- Dr. Davis said she considered every member of the committee a friend.
   She offered to help assist in answering questions or providing more information, and reiterated that members can reach out to her, Dr. Moseley Brown, Steve Schwab, or Senator Dole.
- Dr. Davis reminded the committee of the 250 projects her office is responsible for and dozens of Memorandums of Agreement.
- October is Caregiver Month and in support of this, VEO will provide a calendar of events (most are virtual). Events were developed from committee recommendations, such as the Back to School event in late August, which was developed from this committee's suggestion to address families of children and youth.
- The Center of Excellence for Veteran and Caregiver Research is focusing on the experience of children, youth, and caregivers.
- Dr. Davis asked committee members to reach out to her office if they have opportunities to work together with CVEBs and VSOs, or at home with their Veterans.
- Senator Dole thanked Dr. Davis, calling her a great asset to the committee due to her military and governmental background, extensive experience, and her passion for those the committee serves. Senator Dole then introduced Dr. Kaplan and Ms. DeBord.

## Caregiver Support Program Update

Ms. Jill DeBord, Acting National Director Dr. Elyse Kaplan, Deputy Director

## Dr. Elyse Kaplan, Deputy Director

- Dr. Kaplan introduced Jill DeBord, the Acting National Director of the Caregiver Support Program. She thanked Ms. DeBord for her guidance and leadership.
- Dr. Kaplan provided updates on the Program, what has been done and what is planned. The program has priorities in three areas:
  - Standardization: this has been challenging in the past. Changes were made to:
    - a. Staffing, eligibility, transition stipends, revision of tier structure
  - 2. New CARMA IT system implementation
    - a. Scalable, flexible and sustainable
    - Ability to support the current program and expansion
  - 3. Expansion under MISSION Act
    - Legislation and development of regulations
    - Additional benefits including legal and financial planning services for caregivers
    - c. Training Staff
  - Phase One will take place in October 1, 2020, when the Program is being expanded to include Veterans injured prior to May 7, 1975.

- Phase Two will take place in October 1, 2022, when the Program will expand to include Veterans injured between May 7, 1975 and Sept. 11, 2001.
- Some of the eligibility criteria changes for expansion include:
  - Service-connected disability of 70% or more, and
  - A need for personal care services for a minimum of six (6) continuous months based on either an inability to perform an activity of daily living each time the activity is performed, OR,
  - A need for supervision, protection, instruction...on a daily basis.
- Highlights include:
  - Published final rule July 31, 2020,
  - Takes effect October 1, 2020
  - Need to ensure that Veterans and caregivers know they are not eligible until the date of expansion,
  - Eligibility under expansion is linked to IT systemcommunication,
  - Veterans and caregivers prior to September 11, 2001 should NOT apply prior to the expansion going live, they must reapply if they apply early.
- PCAFC expansion of benefits and services include:
  - Resources extended to caregivers of eligible Veterans, including training, enhanced respite care, counseling, technical support, beneficiary travel benefits, monthly stipend, and access to health care through CHAMPVA.
  - Additional benefits include financial planning and legal resources for primary family caregivers.
- Stipend system modifications include:
  - Previously based on the Bureau of Labor Statistics combined rate, now it will be based on the Office of Personnel Management (OPM) GS rate of Grade 4, step 1, based on the locality pay in the area in which the Veteran resides.
    - This benefits Veterans and caregivers who were compensated significantly less for same the responsibilities due to their area.
    - This makes caregiving more equitable across the nation for all Veterans and caregivers.
  - Changing from three tiers to two levels of care:
    - Level One is lower need, for those not determined to be unable to self-sustain. Primary family caregivers receive 62.5% of the stipend.
    - Level Two is higher need, for Veterans who are unable to self-sustain in the community. Primary family caregivers receive 100% of the stipend.
- Centralized Eligibility and Appeals Team (CEAT):

- There was a previous challenge of lack of consistency, standardization, decentralized process, and success measures were unclear.
- It went from 150 medical centers making decisions to now being centralized to 18 VISNs.
- Interprofessional teams include a medical provider, psychologist, and registered nurse/social worker/licensed professional mental health counselor, and if desired occupational therapist.
  - Working together as teams to determine eligibility
  - Caregiver Support Coordinators focused on providing clinical care and supporting caregivers
  - Enhanced care at local level
- · Staffing has increased:
  - Phase One- from 450 staff to over 1,000 staff
  - Phase Two- current phase-750 additional staff being hired
    - Currently 1,100 staff on board
    - Staff more than doubled in one year
  - Well prepared for the expansion
- Increased governance structure:
  - Full-time VISN leads, larger VISNS may have two leads
  - Established Caregiver Support Program Managers at most medical centers
  - Centralized Eligibility and Appeals Team (CEAT)
  - Every Medical Center is approved to hire a provider to focus on enhancing the Program of General Caregiver Support Services (PGCSS),
    - The program has been a part of the CSP since inception,
    - Previously, CSCs had been focused on administrative duties because of the larger numbers in PCAFCsupposed to be 5,000 and is at 19,500 members,
    - PGCSS Provider purpose is to ensure that the program is available to as many caregivers as possible.

## Ms. Jill DeBord, Acting National Director

- Jill DeBord presented the remainder of the PCAFC expansion update. She
  thanked Dr. Kaplan, Senator Dole, Dr. Davis, Dr. Moseley Brown and the
  committee members and she appreciates the committee's hard work,
  advocacy and commitment to Veterans and caregivers.
- She covered the application process for PCAFC for family caregivers.
  - A Veteran seeking admittance to the PCAFC must:
    - Apply through a new IT platform electronically or manually,
    - The application goes to the Health Eligibility Center (HEC) then to a Medical Center,
    - An initial interview is scheduled by the Medical Center team,

- The team collaborates with the Veteran's primary care team to address all Veteran needs.
- The caregiver support team schedules assessments for both the Veteran and the caregiver: Veteran Psychosocial Assessment, Caregiver Assessment and Veteran Functional Assessment Instrument, a new tool for assessing Veterans' needs, abilities and inabilities.
- All three assessments are sent to the VISN Centralized Eligibility and Appeals Team (CEAT) for an initial eligibility determination.
- If the Veteran is ineligible, the application is sent to the Program of General Caregiver Support Service for communication to the applicant.
- If the Veteran appears to be eligible:
  - The application goes to Medical Center,
  - Core curriculum and home care assessments are scheduled,
  - Home visits are preferred, but due to COVID, the Veteran and caregiver can be assessed via video/telehealth to ensure the home is safe and suitable for providing care there.
- After training and the assessment application going to the VISN and CEAT there is a final eligibility determination, identifying Level One or Level Two.
- The process from application to eligibility occurs over a maximum of 90 days from the application date.
- There is a standardized process for appeals:
  - A letter is sent stating ineligibility which provides information on the appeals process,
  - A first letter of appeal is sent to the facility Patient Advocate,
  - Coordination with VISN Patient Advocate Coordinator and CEAT administrative program staff,
  - The alternate CEAT Team makes determination,
  - Then to Chief Medical Officer (CMO) at the VISN,
  - Letter to Veteran and caregiver comes from Network Director from Veteran's home VISN
- The appeals process should take a maximum of 45 days.
- Second Level appeals follow the same process, but can include another consultation, if the CMO determines it necessary.
- · Hiring staff for growth:
  - To provide staff at VISNs and Medical Centers post-expansion to serve newly joining Veterans and Caregivers,
  - Trainings for new staff include:
    - March 2020- VISN Lead training
    - July 2020- CEAT training
    - Sept 2020- Conference on MISSION Act expansion with over 1,000 participants expected

- Letters communicating the new process were sent to legacy participants (Veterans and caregivers already in the program).
  - As of October 2020, all must be reassessed under the new eligibility criteria with all legacy assessments completed by September 30, 2021.
- VA Central Office (VACO) Program Office Expansion Support planning:
  - Engaging Travel Nurse Corps to fill the gaps in staffing for assessment process,
  - Social Work and Nursing Service Chiefs at local sites to fill gaps,
  - Ensure robust staffing to process assessment and reassessments in a timely manner,
  - New applicants must wait to apply until October 2020 and CARMA must be certified by the Secretary post 10/1/2020.
- VISN Wide Planning:
  - Leads are meeting on daily basis,
  - Network Directors, VISN Directors, CMOs, Public Affairs Officers, Social Work Chiefs, and Nursing Chiefs are included,
  - Ensure utilization of all resources to provide assessments in a seamless and timely manner

Planning discharge of Veterans who are no longer eligible to ensure they are wrapped in services and transitions to services through the general program.

#### Questions:

Dr. Davis: Dr. Davis reinforced that the timing of the application process is going to be critical. This will be widely and clearly communicated across the Veteran and caregiver community. All committee members will be included on every communication for their awareness and so they have what is needed to clearly communicate with their constituents.

Senator Dole: Senator Dole thanked Dr. Kaplan and Ms. DeBord for providing such an important update. Senator Dole was pleased that the committee's first round of recommendations such as centralization of the appeals process is being implemented, and reiterated that staffing increases have been needed for a long time.

Dr. Kaplan: Dr. Kaplan thanked Senator Dole and Dr. Davis for help spreading the word, and for the support and guidance. It has been incredibly helpful knowing there are others invested and engaged in this program.

Senator Dole: Senator Dole moved to the reports of the subcommittee chairs and encouraged the committee to ask questions, weigh-in, and make edits. She indicated there would be dialogue with the committee to finalize these

n : n -
Briefing: Care, Benefits,
Memorial and Service
Resources Subcommittee
Ms. Jenna Dorn, Chair,
Subcommittee 1

recommendations so they could then be moved to a vote and sent to the Secretary immediately.

# Ms. Jenna Dorn, Chair, Care, Benefits, and Memorial Services Subcommittee

- Tremendous progress has been made on the macro level on important programs despite challenges in this virtual environment.
- This subcommittee had the challenge of providing targeted recommendations on the micro issues to set the foundation for concern of what are seen as future needs, even if not solvable in the short term.
- Primarily focused on immediate needs.
- Three Recommendations were developed, with the third being common to both subcommittees.

## First Recommendation Highlights

- This recommendation relates to the tremendous impact the loss of a service member or Veteran has on the surviving family.
- Targeted and focused to provide resources and tools online, self-initiated.
- Target tool for younger demographic.
- Supported by Gabriella Kubinyi and Bonnie Carroll for their vast expertise.
- Focused on two aspects of the process for the tools:
  - Understanding and navigating specific benefit programs that are government-wide and available to families and survivors when they faced an unplanned tragedy.
  - Coping for bereaved children.
- Long term mental health issues are considered.
- There is a need for readily accessible resources that can assist with these challenges.
- The death of a Veteran is a sudden, unplanned event and survivors often do not have time to adjust to the new circumstances, such as suddenly being the sole provider and caregiver to dependents. They may not be aware of the assistance available.
- The subcommittee believes VA has the prominent responsibility of developing these online resources and tools in collaboration with other government agencies, non-profits and private providers. The focus is not on reinvention, it is about easier access to the targeted resources that are already available.
- Bonnie Carroll and Gabriella Kubinyi provided key insights, and Molly Ramsey wrote a compelling recommendation.
- Discussion was opened to the committee for possible missing elements and feedback.

#### Questions

Senator Dole: Sen. Dole noted that valuable insight was provided by Ms. Carroll and Ms. Kubinyi in the development of this recommendation and she hopes that they will continue to work with the Office of Survivor Assistance to advance this recommendation.

Dr. Koffman: How are services provided by non-profits, VSOs and other resources applied currently vetted and leveraged?

- Jenna Dorn: Ms. Dorn deferred to Dr. Davis. She noted that there have been other collaborative efforts across the organization and a process has been developed to ensure those resources are well understood, vetted and carefully described.
- Dr. Davis: The intention to support survivors begins with robust programs at DoD and military services working with programs like Blue Star, Gold Star, and TAPS organizations.
  - VA has a designated office in the Office of the Secretary called the Office of Survivors, a direct report to the Chief of Staff, which ensures the entire Department has all of the information on mental health, benefits and care assistance available.
  - A Quick Start Guide recommended by this committee has been developed to ensure that survivors are aware of all the services available to them.
  - Partnering with individual organizations is done through Memorandums of Agreement which are cleared with General Counsel, taking into account the expertise and reputation of the organization.
  - The VEO engages with the community through CVEBS, VSOs, and our newsletter to make sure local resources are known.
  - Community-based organizations provide benefits, scholarships, etc.
  - Master calendar on VA.gov will detail everything that is happening, both on a local and federal level, through HHA, HHS or any other agency.
  - Master FAQ document is available.
  - The National Resource Directory is being updated to add new programs like the Warrior Canine Connection, an example of a program that offers support for families in grief.
  - Extensive work is done with the Chaplain Corps at the community level, beyond their associations with DOD, military services, and VA Hospitals. For example, clergy training is available on working with Veterans' families during COVID, with many families not able be at the bedside of their loved ones.
  - Work with doctors and care providers continues to ensure virtual connectivity.
  - o There is also a large active human component.

## Second Recommendation Highlights

 Dr. Kaplan and Ms. DeBord gave a brief on the expansion of the Caregiver Program.

- The law requires a two-year gap between Phase One and Phase Two, a significant delay in important benefits for Veterans who served between May 8, 1975 and Sept 10, 2001.
- This is a complicated and complex undertaking and requires IT planning.
- These benefits and services are crucial lifelines for all Veterans and caregivers, both pre- and post-9/11.
- The foundation is now in place. IT programs and certifications issues have been addressed.
- The subcommittee is requesting legislative relief from the mandated twoyear delay:
  - This would have the two-year gap reduced to one year, from October 2022 to October 2021.
  - Vital benefits, training and eligibility should not be delayed.
- Committee could have a significant impact by recommending the expedition of the mandated two-year gap.

#### Questions

Senator Dole: The expansion of the Caregiver Program for all war eras has been a long-time goal of the Elizabeth Dole Foundation, The Independence Fund, the Veterans of Foreign Wars (VFW) and many other organizations. It is good to see movement, but it is not nearly fast enough, especially when there have already been a number of delays. Pre-9/11 caregivers have been caring for the wounds, illnesses and injuries of Veterans for years—many for decades—without any support or recognition. Now those war wounds are being compounded by the effects of aging—mobility issues, hearing loss, diseases like Alzheimer's, cancer, and other issues. This is a very important recommendation, using language that respects the fact that while it takes time and care to do this right, time is also of the essence.

Jenna Dorn: Ms. Dorn noted that if this recommendation is adopted, the committee should use Senator Dole's compelling rationale as part of the document, as it is in real people terms that will be an asset to the document. She then noted that Ms. Comeau will brief on the third recommendation, as it is a common concern of both subcommittees. She acknowledged that caregivers are supporting a long-term system of care informally. It is impossible to sustain a system like that without support, without respite. While some caregivers may be reticent to take respite, it is critical for their own sustainability.

Briefing: Research, Partnership, Community Service and Outreach Subcommittee Ms. Melissa Comeau, Chair, Research, Partnership, Community Service and Outreach Subcommittee

## First Recommendation Highlights

 Expand mental health support to families, caregivers and survivors to include access to telehealth services, substance use disorder treatments, intimate partner violence assistance programs, and crisis interventions in response to the 2020 COVID-19 pandemic and also beyond.

- This recommendation was a direct response to the EDF outlining mental health as the number one concern of caregivers during the pandemic; social isolation is not new to caregivers, but is exacerbated during this time.
- Expand telehealth to think about substance abuse disorders, intimate partner violence, and crisis interventions.
- Rationale explains justification as well as research and studies.
- The Committee hopes to work with VA Office of Mental Health through the Center of Excellence, which could be helpful in understanding how COVID-19 has impacted caregivers, their families, the care Veterans receive, and survivors.
- Ms. Comeau thanked the subcommittee members for their participation in forming this recommendation, as the final language came from many different perspectives.

#### Questions

**Dr. Koffman**: We talk about surveillance and surveillance typically lags way behind. How do we know our efforts are focused and meeting their mark in terms of real-time data?

 Ms. Comeau: The subcommittee listed all the expected outcomes of the recommendation, they are hoping this recommendation will utilize VA and community-based mental health services. This can contribute to greater wellness of family caregivers and survivors that may be coming into VA. Since it is Suicide Prevention Month, it is important to call out all aspects of mental health.

Dr. Koffman: Are there real-time surveys for accurate data?

- Dr. Davis: Families can have open mental health services from VA including telehealth. There are three surveys that are COVID-19 and telehealth related, so surveys are trying to capture the experiences of those using any services of telehealth and/or mental health, we will have data from survey soon.
  - VEO can also do input and process counts to identify what VA was doing to serve the population six months ago vs. what it is doing now.
  - b) VEO wants to see access to services increase such as access to inpatient hospitalization, or even family disruptions, suicide, etc. what we want to get to for outcome and impact, there are metrics—working with Dr. Miller at Office of Suicide Prevention.
  - There is a wide variety of challenges families are dealing with during COVID-19, VEO is looking at surveys not just to provide the

quantitative data but the qualitative data to begin to demonstrate use. This data can detect when an area is underserved.

Mr. Knapp: I lost my son to suicide when he was 20 years old, many college-age kids are separated from parents, we must have telehealth for them. Tracking Veteran suicide and getting data points in the community to see gaps in care can help to prevent suicide in the future.

- Ms. Comeau: An advantage of this subcommittee is the experts who have lived this and continue to live it have helped shape a recommendation that will make a difference.
- Dr. Davis: The Center of Excellence is now focusing on children and youth, and challenges like this, as it will be a great asset to this recommendation.

# Second Recommendation Highlights

- a) Create proactive coordination of care with VA providers for all medical care provided by non-VA providers to include the caregiver, and
- b) All VA care plans include information on, and referral to, non-VA resources appropriate to address and support the whole health needs of the Veteran and the involved family and caregivers with special attention to those transitioning or at risk for suicide.
  - Addresses the coordination of care through VA, various VSOs and community partners.
  - The first part of the recommendation (a) regards clinical care for the Veteran, caregivers are included in VA care with good communication, but for non-VA care providers that is not always the case. Non-VA providers may not recognize the role of a family caregiver and may not understand the relationship or the appropriate approvals. It is disjointed.
    - a) All non-VA providers that care for Veterans to be trained on the role of caregiver, how to include caregivers in care plan and process, how to help caregiver understand the coordination between VA and community providers.
  - The second part of the recommendation (b) indicates that all community
    partners wanting to help caregivers should include non-VA resources for
    family and caregivers, and introduce this population to community
    resources, peers that may be helpful for support, respite, things that could
    benefit both the caregiver and Veteran. Veterans transitioning from DoD
    to VA, who may not be familiar with VA resources, needs to know what
    resources are in the community, Veteran organizations that can help.
  - Always thinking about suicide risk and proactively providing prevention and awareness resources.

 Ms. Comeau thanked the EDF's Campaign for Inclusive Care, which has addressed some of these concerns.

#### Questions

Senator Dole: Thanks to USAA and their incredible support of the transformative Campaign for Inclusive Care, caregivers are included in clinical care from day one. The campaign is expanding across the entire VA system in the coming year. Training community care providers will allow EDF to engage many more caregivers. The caregiver is such an important part of the Veterans' health, and when Veterans seek care outside VA, the caregiver role is no less important.

Dr. Davis: The Dole-Shalala Commission came up with the VA-DoD Recovery Care Plan, intended to do this, albeit with government resources. VA is working with community care vendors to make sure all training is going on at VA/VHA—every single staff will get Own the Moment (OTM) training, training on how to work with caregivers and include them in the conversation.

- Looking to expand OTM training to community providers.
- VA is also providing surveys for Veterans and caregivers that receive care from private provider, the best way to get this right is to ask the people who are receiving care, which is Veterans and caregivers. Caregivers need to be included in the comprehensive care plan.

Ms. Alvarado: Coordination is critical for caregivers because sometimes they are required to make numerous calls to get help. When caregivers go outside of VA, it is a reflection of that; that is why it is important that non-VA providers receive training on OTM.

# Combined Third Recommendation Highlights

- Ms. Comeau introduced the combined recommendation. Both subcommittees put respite at the forefront.
- The recommendation states that VA:
  - Work with Congress to increase the funding for Veteran Directed Care (VDC) so that it can be offered at all VA Medical Centers,
  - Collect data/research to understand the usage of respite services by Veterans and their caregivers to better understand how caregivers access respite and any barriers they may face while using it, and
  - Launch a public awareness campaign to educate caregivers and Veterans on the value of respite care and the array of services offered and available through VA.

- Ms. Comeau said many caregivers feel guilty taking respite care, so a
  public awareness campaign could help with getting rid of the stigma of
  respite, and it should be an expected part of their care journey.
- Veterans often don't want their primary caregiver to take respite because it means they will have to go to a facility or have another caregiver come in, need to bring Veterans into conversation, know the benefits of respite care to caregiver.
- Veteran Directed Care puts control of respite into caregivers' and Veterans' hands, expanding to all medical centers, and adding education on barriers to accessing respite.
- This will provide more control over respite experience and drives use.

#### Questions

Senator Dole: Sen. Dole thanked CareLinx, Mike Linnington with the Wounded Warrior Project, and Harriett Dominique from USAA for seeing the value of respite and investing in the program that EDF has launched.

- It is critical to develop a better communication strategy on what respite care really means, how caregivers will benefit from respite care. We must make it clear what benefits are provided when talking about respite.
- The VDC team should brief the committee on the details of this highly popular program, the concept of VDC and its 90% satisfaction rate.

Ms. Lazare: Ms. Lazare has worked with the VDC program and in addition to the rationale, this has a cost factor lower than Homemaker and Home Health Aide Care. It can provide care for three Veterans in the community for the cost of one Veteran living in a facility.

Dr. Davis: Dr. Davis thanked Ms. Comeau and echoed the Senator's comments.

- October is Caregiver month and VA has events and activities planned through the month that will be highlighting respite care, the Elizabeth Dole Foundation and CareLinx Respite Relief Program, and other partners in the community, and anything else the committee would like to share
- State-wide events are planned for Pennsylvania and Minnesota with an emphasis on caregiver resources.

## Committee Discussion, Mr. Steve Schwab, CEO, Elizabeth Dole Foundation Dr. Lynda Davis, Chief VEO

## Mr. Steve Schwab, CEO, Elizabeth Dole Foundation

- Mr. Schwab thanked the committee for their work.
  - Excited to advance recommendations that range from survivor assistance to adults and children, expanded mental health for families, fast-tracking support for caregivers, and expanding respite support.

- The Wounded Warrior Project is expanding and invested \$7 million in caregiver services and support.
- Other VSOs represented on this committee are working hard for caregivers and families.
- Mr. Schwab mentioned to add the language addressing costs to the rationale of the combined recommendation.
  - The committee added the rational language in real-time during the meeting.
- Ms. Lazare mentioned adding language to the rationale of Recommendation Two from the Care, Benefits, and Memorial Services Subcommittee, to include the timeliness of COVID-19 and how it has impacted caregivers because of their isolation. Caregiver issues have been exacerbated because of this pandemic.
- Mr. Schwab and Ms. Lazare added language on social isolation and loneliness having an impact on caregiver mental health, which has been exacerbated since COVID-19. This drives home the need for care, and it is preventative.
  - Ms. Alvarado said she thought the word 'preventative' should be included in the rationale.
- Mr. Schwab asked if there were any more comments or questions about the recommendations.
  - Ms. Lazare asked if there was an app of some kind where the Veteran or caregiver can coordinate their care.
  - Dr. Davis responded that they do have an app, My VME Calendar, and requested the DFO to send out a list to the committee.
- Mr. Linnington thanked Ms. Comeau for working on the subcommittee.
   The \$7 million going towards caregiver programs from WWP would have never happened if it wasn't for the data and research being presented by this committee. The committee is making a difference.
- Ms. Comeau mentioned that the committee needs to stop using "burden" when taking about Veterans and respite care. Whether it is in language or written, people should never think of a Veteran as a burden. It is critical to look at the language when creating the awareness campaign.
  - Mr. Schwab agreed and said he would take a second look after the recommendation.
  - Dr. Davis said to follow up with Own the Moment Training to make sure they avoid the word "burden" when talking about Veterans.
- The committee voted to advance the five recommendations and the vote was unanimous.
- Senator Dole thanked the committee and noted how much they have accomplished. She reiterated that because of the fast-track, we would now be able to forward the five recommendations to Secretary Wilkie immediately.

	<ul> <li>Senator Dole said she would follow up to inform members on the status of the recommendations and to identify dates for the next committee meeting.</li> </ul>
Wrap up & Adjourn	The meeting was adjourned at 3:04pm EDT by Senator Elizabeth Dole, Chair.

Approved

Dr. Betty Moseley Brown, DFO

Approved

Senator Elizabeth Dole, Chair

Elizabeth Dola